

# CHES: A Computer-Based System for Providing Information, Referrals, Decision Support and Social Support To People Facing Medical and Other Health-Related Crises

David H. Gustafson<sup>1</sup>, Kris Bosworth<sup>2</sup>, Robert P. Hawkins<sup>1</sup>, Eric W. Boberg<sup>1</sup> and Earl Bricker<sup>1</sup>

<sup>1</sup>Center for Health Systems Research and Analysis  
University of Wisconsin  
Madison, Wisconsin

<sup>2</sup>Center for Adolescent Studies  
Indiana University  
Bloomington, Indiana

## ABSTRACT

*CHES (the Comprehensive Health Enhancement Support System) is an interactive, computer-based system to support people facing health-related crises or concerns. CHES provides information, referral to service providers, support in making tough decisions and networking to experts and others facing the same concerns. CHES will improve access to health and human services for people who would otherwise face psychological, social, economic or geographic barriers to receiving services.*

*CHES has developed programs in five specific topic areas: Academic Crisis, Adult Children of Alcoholics, AIDS/HIV Infection, Breast Cancer and Sexual Assault. The lessons learned, and the structures developed, will serve as a model for future implementation of CHES programs in a broad range of other topic areas.*

*CHES is designed around three major desired outcomes: 1) improving the emotional health status of users; 2) increasing the cost-effective use of health and human services; and 3) reducing the incidence of risk-taking behaviors that can lead to injury or illness.*

*Pilot-testing and initial analysis of controlled evaluation data has shown that CHES is extensively used, is useful and easy-to-use, and produces positive emotional outcomes. Further evaluation is continuing.*

## INTRODUCTION

Effective health care delivery increasingly involves a partnership between providers and consumers. Effective treatment often depends on a consumer making well-informed, difficult decisions. The increasing complexity of treatments, as well as a proliferation of treatment options, often leaves consumers of health care services at a severe disadvantage in attempting to make

optimal treatment decisions. The barriers to accessing the information and support necessary to make these decisions can be difficult to overcome. These barriers include limited accessibility, complex material that is difficult to understand, need for confidentiality and limited financial resources [1], as well as ability to act under stress, and the belief that actions must be taken immediately [2]. A computer-based support system can overcome or reduce many of these barriers, providing information and support that is convenient, comprehensible, timely, non-threatening, anonymous and controlled by the user.

**Convenience** Information required to make many decisions regarding medical issues is often inaccessible. Local libraries seldom have current or in-depth medical information. Medical libraries usually have the information but don't encourage public use. Geographic distance and limited hours often create additional barriers. A computer system, available in the home or in public sites such as libraries, community centers and clinics could provide a single convenient source for in-depth, accurate, up-to-date information.

**Comprehensibility** Medical terminology is often a significant barrier to understanding, decision making and maintaining a sense of control. People in crisis often lack energy for deciphering incomprehensible information. Medical literature is not reader-friendly and clinicians often lack training to communicate information in ways patients understand. Complex information must be presented in forms people can understand. In a well-designed computer system, complex information is broken down into easy-to-understand pieces. Users with different levels of knowledge and understanding can proceed at whatever pace they choose.

**Timeliness** Information has its greatest impact if provided when people are ready to use it.

People in health crises often complain about information overload. Despite their many questions, people are often too upset to know what to ask or to understand the answers given. Their questions and readiness to comprehend answers do not always coincide with their clinic visits. A computer system can be far more accessible than a doctor or social service agency. If the computer is in the home, it is available 24 hours a day. Even when placed in public sites, the computer could be available daily, and much more readily than direct contact with providers.

**Non-threatening** People need a comfortable environment to seek and assimilate information. But clinicians and clinics can be intimidating under the best of circumstances. Clinicians often seem to hold a monopoly on medical information. Because clinicians increasingly operate under stress and pressure, they may seem uncaring and intimidating. As a result many people rarely take the chance to raise major concerns that effect key decisions. A computer offers a safe and non-judgmental source for information and support.

**Anonymity** People are often too embarrassed to ask questions openly. Fear of appearing ignorant, or embarrassment about openly discussing sensitive issues (like sexuality) can significantly inhibit access to information and support. By providing this information and support anonymously, a computer system significantly reduces these fears.

**Control** By definition, a crisis means that one's life is suddenly out of control. Yet encounters with conventional information delivery can exacerbate the problem. Users have little control over the extent, depth or speed of information they receive. Yet people understand more, and make better decisions, when the information and support environment allows them to control how they receive and assimilate information. A computer-based system allows users to proceed at their own pace, dealing with issues when, how and in what order they wish.

A computer-based support system which can provide convenient, comprehensible, timely, non-threatening, controllable and anonymous information and support is being developed by a team of decision, information, education and communication scientists along with nurses and physicians [3]. This system, known as CHES (the Comprehensive Health Enhancement Support System), is a PC-based system, with individual units connected by modems to a central "host" computer to allow anonymous communications with other CHES users. Color, graphics and simple user-prompts make CHES appealing and easy to use, even by people with no computer experience.

CHES is an integrated set of computer services that allows users to: anonymously talk with peers, question

experts, learn where to get help and how to effectively use it, read stories of people who have endured similar crises, read relevant articles, examine their risks, think through difficult decisions, and plan how to regain control over their lives.

By providing medical consumers with an effective means of obtaining medical information and support, CHES is designed to effect three major outcomes.

**Improved Health Status** In making informed choices, the consumer will benefit by obtaining the best possible care. CHES provides a broad range of accessible information to help make decisions. Communication with others in similar situations is an additional source of information, as well as a means of reducing feelings of isolation, depression and anxiety. Thus, CHES use can result in both better physical and emotional health status.

**Improved Health Behavior** CHES can provide consumers not only with information on behaviors which will help maintain or improve their health, it provides them with tools (Decision Analysis, Implementation Analysis and Social Support) to assist them in implementing and maintaining those behaviors.

**Cost-Effective Service Utilization** In this era of spiraling medical costs, CHES can be of enormous value in guiding consumers to the right services at the right time. CHES can also help train users to be more effective users of services. Well-informed patients will need to spend less time asking questions of physicians, nurses and social workers. They will can also learn what preparations to make and what documentation to bring with them in order to get the most out of appointments. CHES can even record on-going health status data (symptoms, medications, weight, etc.) to help providers in making diagnosis and treatment decisions. CHES can also provide a cost-effective means of health information delivery in rural areas, where doctors and clinics are often far away from the patients.

## CHES

The CHES program is designed as a "shell," containing a wide range of integrated services, into which content on specific topics can be easily programmed. Content in five specific topic areas is currently being programmed and tested: 1) Breast Cancer; 2) AIDS/HIV Infection; 3) Sexual Assault; 4) Substance Abuse; and 5) Academic Crisis.

The content in each CHES topic area is shaped by an extensive needs assessment process of the information and support needs of people in health crises. This process includes survey research, focus groups, and one-on-one interviews. Programs are then developed by a team which includes experts in each topic area, as well

as experts in decision analysis, evaluation and health systems. Programs are periodically reviewed by both experts and people affected by the crisis to insure that the content was both accurate and accessible.

The CHESS system includes 9 services :

Questions and Answers (QA) is a compilation of answers to many common questions about each topic in CHESS. Questions can be accessed either by a key word search or through a hierarchical topic structure. Answers are brief 1- to 5-screen overviews, with references to where more detailed information can be found, both in other CHESS services and outside CHESS.

Instant Library (IL) is a database of articles, brochures and pamphlets. Articles cover a broad range of topics and levels of complexity, and are drawn from scientific journals, newsletters and the popular press.

Getting Help/Support (GH) helps users understand what services are available, how they work, how to find a good provider and how to be an effective and active consumer. GH also contains a Bulletin Board (BB) of current events and news items.

Personal Stories (PS) are real-life accounts of living and coping with the crises covered in CHESS. These stories were collected and written by trained journalists. Users can read 300-500 word overviews, and more detailed "expansions" on specific topics. Stories are indexed by both topic and demographic characteristics.

Expert Mail (EM) allows users to ask experts anonymous questions and receive confidential responses within 24 hours. Questions are answered by experts in each topic area. If these experts are unable to answer any questions adequately, a panel of experts with a wide range of expertise is available to call on.

Discussion Group (DG) allows anonymous, non-threatening communication among people affected in each topic. Message senders are identified by a code name. Users share information, experiences, hopes and fears, give and receive support, offering different perspectives on common issues. A trained facilitator monitors groups to keep discussion flowing smoothly.

Decision Aid (DA) helps people through hard decisions. Users consider their various options and the factors (considerations) which affect which option they will choose. Two different types are available. "Tailored" Decision Aid programs help users with specific decisions that frequently need to be made by people facing each crisis or concern (which type of surgery for a woman with breast cancer, for example). The second Decision Aid model can be used for any decision. Both programs use multi-attribute utility models [4] for the analyses.

Action Plan (AP) helps users implement a new decision. Action Plan is based on change theory [5], and asks users how they propose to implement a decision,

helps them analyze their strengths and weaknesses, supports and barriers, predicts the likelihood of success and suggests ways they can strengthen their prospects.

Assessments (RA) allow users to assess lifestyle risks and situations. For example, assessments are available on the risk of exposure to or transmission of HIV. Users answer a series of detailed questions on behaviors which transmit HIV. A Bayesian model [6] then predicts the risk based on the reported behaviors. Users are offered detailed feedback on their risk factors and how to reduce them. Users can also go back, change their answers, and see graphically how changes in behavior can reduce or increase their risk.

The CHESS system requires personal computers with 386sx microprocessors running at 20 MHz, 2 MB RAM, color VGA monitor and a 2400-baud modem. Communications are transmitted via modem to a "host" computer (also a 386sx PC) with multiple modem connections. Network communications are supported by commercially available communication software, specially modified to be easier to use.

## SYSTEM EVALUATION

### Pilot Tests

CHESS has been extensively pilot-tested with both women with breast cancer and people with AIDS/HIV infection. Both groups used the system frequently, perceived it to be very useful, and experienced positive emotional outcomes from CHESS use. Thus, 10 women with breast cancer used CHESS services 546 times during a 50-day pilot test, an average of 1.2 uses/subject/day. Similarly, 11 men with AIDS/HIV infection used CHESS services 581 times during a 34-day pilot test, an average of 1.6 uses/subject/day, for an average time of use of 20 minutes/subject/day. These results are especially encouraging since the content of the information and referral components was incomplete at the time of these pilot tests. The Communication services were the most frequently used CHESS components, accounting for 61% and 75% of the uses in the Breast Cancer and AIDS/HIV tests, respectively. Use of Information and Referral Services accounted for 30% and 18%, respectively, of uses, while use of Decision Support services accounted for 9% and 7%, respectively, of uses in these pilot tests.

In post-test surveys, subjects in both Breast Cancer and AIDS/HIV pilot tests reported CHESS to be very useful. Measured on a 1-7 scale (1 = not useful, 7 = very useful), most of the CHESS services were rated at least 6.0. Both the Communication and Information Services were highly rated. Post-test interviews with all subjects also reflected extremely positive reactions to CHESS from most subjects.

CHESS users have reported positive emotional outcomes in all pilot tests to date. The emotions most frequently felt by women with breast cancer while using CHESS were empathy, support, motivation and understanding, each rating at least 5.0 on a 1- to 7-point scale from never (1) to very much (7). Similarly, men with AIDS/HIV reported feeling support, understanding, relief and empathy most frequently. The emotions felt least while using CHESS were boredom, indifference, stress and pity (women with breast cancer) and helplessness, boredom, pity and fear (men with AIDS/HIV infection), each emotion rating below 2.5 on the 1 to 7 scale.

In addition to studying CHESS use in home settings, we are also investigating placement of CHESS in community sites. A 6-week pilot test looked at use of CHESS at 14 locations on the University of Wisconsin-Madison campus, including residence halls, libraries, health clinics, athletic facilities and campus-based social organizations. Almost 1500 uses were registered, with the greatest amount of use at a Computer Resource Center and in dormitories (Table 1). Academic Crisis, AIDS and Sexual Assault were the most-frequently-used programs, accounting for 22%, 17% and 16%, respectively, of system uses. In contrast to in-home pilot tests, Information Services (IL, QA, PS, GH) accounted for the largest percentage of uses, 48.1%. Communication (DG, EM, BB) and Analysis (DA, AP, RA) services accounted for 32.5% and 19.4% of uses, respectively. These results are most likely due to a much larger number of one-time and infrequent users of the system in public sites, compared with the relatively long-term in-home installations.

**Table 1: University Pilot Test Use**

Location	Number of Uses
Computer Resource Center	288
Men's Dormitory Lounge	207
Co-Ed Dormitory Lounge	192
Computer Center-Women's Dorm	128
Women's Dormitory Lounge	123
Athletic Training Facility	115
Campus Assistance Center	114
Private Residence Hall Computer Lab	96
Sorority	57
Fraternity	50
Married Student Housing Lounge	47
Center for Cultural Enrichment	33
Student Counseling Center	33
Student Health Center	11

## Controlled Evaluation

A more detailed, controlled evaluation of the outcomes of CHESS use in men with AIDS/HIV infection is currently under way. Half of 60 subjects were given CHESS to use in the home for 6 months, half received nothing. The system was concurrently pilot-tested with 9 women, all of whom received CHESS. All subjects were given pre-tests and 2-, 5- and 9-month post-tests measuring health status, health risk behaviors and health service utilization. Over six months, the 30 men and 9 women used CHESS services a total of 5,520 times (Table 2). Approximately 85% of the uses were Communication Services, 13% Information Services and 2% Analysis Services.

**Table 2: AIDS/HIV Study Use of CHESS Services**

Service	Number of Uses
DG	3,767
EM	493
BB	407
IL	240
PS	223
QA	203
GH	76
AP	45
DA	36
RA	30

The preponderant use of Communication Services mirrors the results seen in other in-home tests, and appears to be a function of the long-term, in-home use (see different use patterns in UW-Madison pilot test above). Thus, while a Personal Story or Instant Library article would be read only once or twice, and all stories or articles could be read in a few "uses," Discussion Group was used several times a week throughout the study by many subjects. This may reflect less on the inherent values of the different services than on the fact that the content of the Information and Analysis services was constant, while that of the Communication Services was constantly changing, with new messages being posted every day.

Analysis of two-month post-tests indicates several significant positive outcomes (Table 3). Sample size was not large enough for several promising trends to be statistically significant, but some of these are also included in Table 3. An additional 120 men and 40 women will be recruited from the Milwaukee area and studied in order to increase sample size. Analysis of 5-month post-test data is just beginning.

**Table 3: AIDS/HIV Study Outcomes**

<b>Significant Effects of CHES after Two Months:</b> *Decreased Negative Emotions *Increased Cognitive Functioning *Decreased Interference of AIDS in Daily Life
<b>Encouraging Trends:</b> *Decreased Recidivism to Unsafe Sex *Decreased Frequency of Anal Sex *Decreased Visits to Primary Care Physicians *Increased Perceived Control over Health Care

### FUTURE DEVELOPMENT

CHES has always been envisioned as a "shell," a set of services into which content specific to a wide range of topics could be easily programmed. The similar results (high use and positive emotional outcomes) seen in two widely differing populations (women with breast cancer and men with AIDS/HIV infection) support this premise. Even though the populations are different, and many of the specific issues facing each are different, the underlying needs and concerns of people in health crisis are often similar. The processes utilized here for determining those needs, the set of services which have been developed to meet them, and the methods for adapting the services to specific populations, provide the basis for a support system applicable to almost any health-related crisis or concern.

While refining and development of the basic structure of CHES will obviously continue, the basic "shell" structure of the program is now complete. This allows for the relatively easy addition of modules covering new topic areas. Medical advisors to the project have variously suggested a variety of future topics: Diabetes, Lymphoma, Prostate Cancer, Cardiovascular Disease, Stress Management and Pre/Post-Natal Care. Addition of more topic modules to CHES will also further facilitate widespread dissemination and acceptance.

### SUMMARY

CHES is a computer-based support system to provide information and support to people facing medical and other health-related crises. It consists of an integrated set of services to provide information, referral, skills training, decision support and social support to its users. These services comprise a "shell" into which content specific to a wide range of topics can be programmed. Though still in development, CHES has already demonstrated its appeal, usefulness and usability in several pilot tests.

Ultimately, the best measure of the effectiveness of CHES comes from users, like the HIV-positive man who left this message in the Discussion Group:

*"I'm proud to say I've gotten as far as I have in the past couple of months because of this CHES program. I feel as if I've grown by giant leaps and bounds, as if a whole new person has come out from inside me, it was always there but never came out, something like a spring flower. Thanks for all your great support and advice. I know I'm only at the beginning of my growing stage but I'm hoping for a good growing season. Coming out so honest to this machine is what I feel has broken the barrier I had set up for myself, then this machine came alive and became real, and now suddenly these real people really know me, WOW! I'm finally started going to groups and meeting lots of new people, and getting my life going again. I guess when I found out I had this disease, I decided I was dying so I figured I'd beat death at its own game, by dying before I was dead. Well, now that I'm back with the living, I've got some things to catch up on. I'd like to work harder at coming out and to help educate others so they don't have to go through this hell. If I can get through to only one person it would be worth it."*

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